Workshop on Long-term Preservation & Management of Electronic Health Record

April 5 -6,2011

Possible discussion topics derived from registrants' opinions on what is needed and what impedes preservation and research use of The EHR

Breakout session 2: Preservation and Reuse of the EHR for Research

Question 1: What is the single most important thing that needs to be done to enable preservation and reuse of EHR?

Registrants for this workshop identified a variety of actions as most important for preservation and reuse. Perhaps the most general was "Development and application of principles of data stewardship." More specific needs included:

- An industry and government-wide definition of what an EHR is and how long it should be preserved;
- Agreement on the objectives of preserving the EHR, which would inform decisions on what to keep and how to keep it;
- Determination of whether all data in the EHR should be preserved and what representations of the data should be preserved;
- Establishment of universal standards for preservation of EHR data;
- Determination of system requirements and functionality necessary to preserve the designated data;
- Identification of what metadata needs to be preserved with the records; and
- Documenting the process for preservation, testing to confirm preserved data can be retrieved, and implementation of access controls for archived data.

Other suggestions asserted that the most important actions to take are in the area of technology:

- Adaptation or supplementation of the Open Archival Information System standard for the specific requirements of preserving and using EHR;
- Managing technology obsolescence across the value chain.
- Identifying file formats and standards at risk of obsolescence.
- Standards for data/metadata formats + format review/migration plans that preserve necessary anonymity while permitting accurate identification of other data elements;
- Standards that integrate imaging and graphics with web compatibility and rich metadata. Web3D.org's X3D and its adoption around the world (esp Europe and Asia) is a great example of how the long-view of data durability (e.g. ISO) can meet the immediate needs of interoperability;
- Media shifts to mechanisms to access old data so that they remains available;
- Information architecture to support preservation;
- A central repository for preservation of health records; and
- A strong, standardized and digitized information system.

Discussion

- *Do you agree that these suggestions identify important actions needed for preservation and research use of the EHR? Would you add any others?*

- *What could be done to move forward in any of these areas?*

Question 2. What is the single greatest obstacle to preservation and reuse of EHR?

Many individuals cited the lack of standards as the single greatest impediment to preservation and reuse. Particular concerns included:

- Lack of data standards;
- the need for a comprehensive and consistent set of standards;
- specific inconsistencies among standards; and
- failure to adhere to standards.

Others identified human and institutional obstacles to long term preservation and research reuse, including:

- Lack of foresight;
- Resistance to change;
- Insufficient dialogue among different stakeholders;
- Uncertainty concerning what should be preserved and how; and
- Failure to articulate policies that show how preservation works and is consistent with other requirements such as privacy and security.

Other responses identified technological obstacles, including:

- Rapid changes in technology;
- Inadequate approach to managing obsolescence;
- Uncertainty over what will work in the long run; and
- the impact on security mechanisms.

Discussion

- *Are there other major obstacles to preservation of the EHR and its reuse for research?*

- *Do you have suggestions for actions that could be taken in the short term to overcome these obstacles?*